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ABSTRACT

This report uses case illustrations to present ten policy issues concerning inclusion of children with disabilities in early childhood education programs. Policy issues were identified from interviews with over 150 families, teachers, and district and state education agency administrators, as well as through many classroom observations. An introduction examines the social-political aspects of education, policy versus practice, and the changing social context. For each issue there is a brief explanation, some data, and a case example of an actual child. The policy issues address the following areas: (1) categorical programs, (2) categorical funding, (3) categorical thinking, (4) the cultural context of education, (5) the community context of education, (6) professional development and practice, (7) litigation and inclusion, (8) regulation and compliance or accountability and quality, (9) the ebb and flow of public dollars, and (10) costs of inclusion. A glossary defines common terms associated with inclusive early childhood education. (Contains 12 references.) (DB)

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PORTRAITS of INCLUSION

through the eyes of children, families, and educators

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PORTRAITS of INCLUSION through the eyes of

through the eyes of children, families, and educators

EARLY CHILDHOOD RESEARCH INSTITUTE ON INCLUSION

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March 1997





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RESEARCH INSTITUTE ON
INCLUSION developed this
preliminary report, based on research it
conducted over nearly two years. The
research involved 112 children and their
families, in 16 programs and school districts, in 5 states across the nation.

The children and families, educators, and administrators represented in this report were asked to participate because of their involvement in inclusive school programs. They represent our nation's diversity in terms of ethnicity, socio-economic status, languages spoken, and geographic location.

Because the portraits in this report are about individual children, families, and programs, its applicability to the nation as a

whole may be questioned by some. We would respond that these stories relating individual experiences are relevant to many because the schools and educational systems in which they originate are shared by many.

It is our intention that this document represent the children, their families, and their schools with fidelity. We also intend that information and stories we present broaden ideas and stimulate dialogue about challenging social issues. Our overriding hope is that the report helps to illuminate differing philosophies about how and where children should be educated. So to the children, families and educators, we give our thanks for your participation. And to those of you who read and learn about their perspectives, we give our thanks for your consideration.

The Early Childhood Research Institute on Inclusion is funded by the U.S. Department of Education through Grant #H024k440004. This report does not express the views of the Department of Education. It is based on preliminary findings from research conducted by the following institutions and persons (in alphabetical order within sites):

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ABOUT THIS REPORT

MERICAN PHILOSOPHER AND EDUCATOR
JOHN DEWEY DESCRIBED LEARNING AS A
"PROFOUNDLY SOCIAL EXPERIENCE." Children learn what is important and permissible to society, how and when to behave in certain ways, how to influence and how influential they can be,

where they belong and where they are allowed to belong — all these and more — through relationships with others.

The social context of child care and classrooms is essential for developing the values we say are important for our children now and as future leaders. These essentials — citizenship, friendship, responsibility, leadership, empathy — are difficult to measure. But as population density increases and we have to share less space and fewer resources with more people, many of whom are different from us in their skin color, language, customs, and abilities, these differences of character become more apparent and more important.

This is one of the preliminary findings of the Early Childhood Research Institute on Inclusion: readiness to learn — which we define as the long-term ability to prosper in educational settings — is an important process that families and educators value for their children. But there are other important outcomes as well. For many families and educators with whom we spoke, ensuring that children have opportunities, as well as skills, to participate in activities that are meaningful to them and valued by society is a priority. They are interested in exercising a right they believe to be fundamental in our society — the freedom to enter and remain in typical settings — because they believe that is where children learn much of what is important to learn.

This right may come into question when a child is designated as one of more than 600,000 young children in our nation with a disability or delay who is eligible for early childhood special education services. Advocates for early childhood education focus on such goals as social and emotional development, young children's self-esteem, and achieving family-centered programs. These goals are precursors to the values and priorities espoused by leaders of the influential education reform movement, which focus on helping children compete in a technological world. But the picture is complicated by cultural understandings and legal definitions of who is disabled; the availability of funds to pay for special services; the competition among categorical programs for finite resources; the discomfort among professionals required to think and act outside the boundaries of their disciplinary training and beliefs; and the demands of educating children in an increasingly complex and rapidly changing society.

Policy is a word that conjures images of important others making decisions that will influence the course of history. Policy makers are believed to manipulate issues they know only in the abstract. But policy is



also affected by the actions of teachers, family members, and others involved in the everyday process of inclusion.

With respect to education policy for children with disabilities, every time a decision is made to test a child, to label and sort a child as belonging in this or that category, or to place a child in this classroom rather than that classroom, a policy is interpreted and enacted. Educators are *de facto* policy makers every day. The integrity of a given policy is dependent in part upon educators' awareness and understanding of the policy; their knowledge and competence in interpreting it consistent with the spirit and intent of the policy; the temporal, monetary, and organizational resources they have available to support the policy; and the reconciliation they make when discrepancies between the spirit and intent and the reality of implementing policies during their daily work inevitably arise.

In this report, we seek to demystify the vagaries and complexities that surround education policy, and at the same time, remove the rose-colored glasses through which advocates of inclusion sometimes portray inclusive education services. Our strategy is to present 10 policy issues — gleaned from an analysis of more than 150 in-depth interviews with families, teachers, and district and state education agency administrators, and many hundreds of observations of children and teachers in classroom settings — and to use real case studies to illustrate how these policies influence the lives of young children with disabilities and their families and schools.

This report is based on themes initially identified in Washington State and supported by data from other study sites. It is part of more comprehensive research conducted by the Early Childhood Research Institute on Inclusion. The research and products generated by this institute, as with most education research institutes, are likely to reach primarily academic audiences. It is our intent in this report to make information accessible and useful to elected and appointed, as well as *de facto*, policy makers — including legislators, program administrators, educators, and families concerned about education policies for young children.

More comprehensive information generated by the Early Childhood Research Institute on Inclusion, and additional copies of this report, are available through:

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All the names of people, programs, and localities have been changed to protect the privacy of those involved. The photographs were taken at a variety of project sites and do not represent the children featured in the report.



THE SOCIAL-POLITICAL LANDSCAPE OF EDUCATION

CHILDHOOD EDUCATION. Most public policy makers accept the link, indicated in a growing body of research, between early learning experiences and later school and workplace achievement. State governments spend more than \$2 billion a year on early childhood programs to prepare young children to succeed in school and to promote their healthy development.

These programs also address sweeping social changes that are shaping the lives of young children, as more mothers move into the workforce, as more families face poverty and eroding real income, and as schools and communities become more economically and culturally diverse. Public policies focus increasingly on early childhood education as the earliest possible intervention to prevent such social problems as juvenile violence, school failure, and welfare dependency.

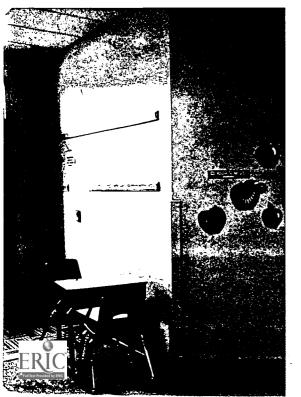
Early childhood programs thus have a more complex mission than ever before. They must comply with a proliferation of federal, state, and local rules that often conflict with each other, and in most cases, were intended for older populations. They must finance growing responsibilities with public and private resources that are separately administered and monitored. And in this confusing and demanding environment, they attempt to meet the needs of a growing number of children who qualify for special education services and an early childhood education mandated by state and federal law.

More than 600,000 young children (3-5 years old) are enrolled in special education throughout the United States, accounting for about 11% of total U.S. special education enrollment. The number of young

children enrolled in special education has grown rapidly in the past decade. During this time, advocates and families have encouraged policy makers to alter both the design and objective of special education for all age groups. Historically, children with disabilities and the special education programs that serve them were characterized by physical and political separation from typically developing children. Today, early childhood programs are often the first venue for the policy of inclusion of children with disabilities in typical school and community settings.

Policy versus Practice

Inclusive school practices evolved from a principle included in the landmark Public Law 94-142, the 1975 Education for All Handicapped Children Act, reauthorized and renamed in 1990 as the Individuals with Disabilities Education Act (IDEA). IDEA guarantees children receiving special education — including young children with disabilities — will receive a "free appropriate public education" in the "least restrictive"



environment." The bind is ensuring that children have unimpeded and supported opportunities to participate in activities and belong in peer groups and still receive the individualized attention they need to acquire developmental skills.

Placement in the "least restrictive environment" is fundamental for learning from and about the greater community and culture, but some educators and parents are concerned that the practice may compromise the learning of basic skills by children with special needs — and by their typically developing peers.

Inclusion is at most an implicit concept in state and federal special education law, and we have no widely agreed-upon definition of inclusion that is applied in all environments in which children with disabilities and those without disabilities come together. We are better able to define characteristics of inclusive environments — that no child is rejected because of a disability, that children with disabilities are represented in natural proportions (about 10% to 12%), that children with disabilities are invited to and supported as they participate in typical early childhood

Inclusion is at most an implicit concept in state and federal special education law, and we have no widely agreed-upon definition....

activities, that children with disabilities have the opportunity to attend child care and schools in their own neighborhoods.

Any public policy essentially represents only a wish — a goal that what the law says will be met. Inclusion is a goal that only some of the schools and programs identifying themselves as inclusive have achieved. The successful ones have been able to make creative use of resources and collaborative approaches. Others have met the goal of inclusion "on paper" only, adhering to the

letter of special education guidelines but leaving children and families isolated in spirit.

The Changing Social Context

Among all students with disabilities, only about half are diagnosed with disability-related problems that began before they were 6 years old. When children begin school, they enter the door of social research that accompanies publicly funded services. Researchers study demographics, health status, and educational and developmental progress. These data show that the number of children in early childhood special education programs has increased in the past two decades along with poverty, a growing share of single-parent families, substance abuse (particularly among pregnant women), and reported prevalence of domestic violence.

Among families with these risk factors, there is a higher percentage of children with identifiable disabilities and a greatly disproportionate number of children who are made eligible for special education and related services because of poor performance on developmental tests. During the past decade, according to U.S. data collected through the national Kids Count Project, conditions that place families under stress have greatly increased. The rate of low birthweight births has increased despite focused efforts in many states to bring more women into timely prenatal care. Birth rates for unmarried teenagers were rising until





recently, and the share of families headed by single parents is still increasing. Nearly a third of the nation's children lived in poor or near-poor families (with incomes at or below 150% of the federal poverty line) in 1995. About 1 of every 6 children lived in a household with no adult male present, and about 1 of every 14 lived in a neighborhood where more than half of all families with children were female-headed.

Many children persevere against poverty, inadequate caregiving, cultural barriers, and other conditions that affect their readiness to learn. Nonetheless, the growing number of children and families at risk is putting increasing pressure on school districts. Administrators reach into special education funds, when possible, to finance a broad range of special services for children with special needs. This is one of the factors driving enrollment in special education nationwide; enrollment for 3-21 year-olds has grown by nearly 70% since the mid-1970s, a period in which over-all school enrollment has been largely stable.

Public schools' expanding role as a provider of and conduit for social services is not the only driver of special education enrollment. Advocates have learned to work with families to identify and demand services state and federal laws guarantee to children with disabilities. Vigorous "child find" required by IDEA and coordinated by school districts identifies children who need early intervention services. And by some accounts, medical advancements since the 1970s that save many premature and medically vulnerable children from death have contributed to the rising number of children with special needs attending school.

The Changing Political Context

Federal and state laws establish most special education policies, and local school districts provide the services and usually contribute to meeting costs. Americans spend about \$32 billion on special education services every year. But President Clinton requests only \$3.2 billion for fiscal 1998 through IDEA. Advocates have fought hard to preserve special education grants to early childhood programs, which amount to about

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\$375 million in the 1998 budget request, as well as IDEA "Part H" funding for identification and early intervention services of 0-3 year-olds (about \$325 million).

State governments assume about 56% of special education costs on average. They convey money to local school districts according to funding formulas that differ in every state. Local school districts must spend their own resources to make up the difference between the real costs of providing special education and state and federal outlays. Before district budgets can be tapped, however, local communities must support this investment. Communities that provide the

strongest support for special education are often those in which diversity, and the participation of people with disabilities in the breadth of community life, are highly valued.

During the 1980s and '90s, public education spending has been subject to intense scrutiny. As with health system reform, policy makers



are looking for value. cost-effectiveness. and measurable performance outcomes. Reformers are looking to changes in big funding streams, such as Medicaid and special education, to curb spending. In contrast to the direction of most educational policy in the 1970s and 80s, federal lawmakers increasingly support devolution of authority over programs and resources to states and to local communities. This trend places special education policy more within the influence of local political culture.

The Changing Educational Context

In the midst of the public debate over authority and spending on special education, services at the classroom level are undergoing fundamental change. For a decade after passage of comprehensive federal legislation, special education implemented a "pull out and fix it" model—using segregated learning environments in separate classes and "resource rooms," usually under the supervision of a special education teacher. When teachers deemed it possible, special education students were gradually integrated, or "mainstreamed," into regular classrooms, to the extent their presence fit in with established curriculum, teaching practices, and teacher preferences.

In the 1990s, this direction has been gradually replaced by the reverse approach: starting most students in regular classrooms and removing them to restrictive environments to the minimum extent necessary. Many early childhood special education programs, which were incorporated into the national system by 1986 amendments to IDEA, have developed according to this model. Today, more than two-thirds of special education students receive services in general education classrooms about 40% of the time. It is not yet known how inclusive policies affect the costs of special education.

Inclusive school practices are gaining acceptance, but they require a rethinking of education policy by all those involved. Administrators must learn to blend categorical education funds into single, inclusive classrooms, despite the pressures of monitoring and audits. And inclusive programs require advocates and families to set aside long-established patterns of "fighting" for special services to embrace systems that are flexible and collaborative.

The promise of inclusive education is that, by providing services tailored to the needs and aspirations of each child, learning will become richer for all. But is it possible to achieve this standard in systems that are buffeted by politics and tightening resources?

We have identified 10 policy themes related to preschool inclusion. These themes may be understood in the context of social policy, the political environment, and special education. They are intended to shed light on the places where inclusion policies and reality converge — in community schools and classrooms.



CATEGORICAL PROGRAMS. Federal and state laws mandate services, but they cannot ensure effective coordination at the school level.

special Education Policy for young children who need individualized assistance to develop and learn is guided by a cluster of federal and state laws. These laws, generated over the course of three decades, are periodically reauthorized and amended. They embody the basic, widely accepted principles of a "free appropriate public education," placement in the "least restrictive environment," regular assessment, documented educational goals, evaluation of outcomes, and due process.

- The nation's 15,000 local school districts are responsible for determining, through assessments, what children are eligible for special education services.
- Local districts must provide eligible students with the services mandated by federal and state policies.
- Several programs and services may be combined to make inclusive program options available to young children. This process sometimes brings conflicting philosophies and educational models together and results in multiple program placements and transitions.
- At the local level, early childhood special education programs are implemented in tandem with Head Start and other educational programs for low-income children.

Implementation of special education policies, and financing for services, is often linked to categories of disability. Some state governments are attempting to change this policy. Recently, several independent research studies as well as documents prepared by the federal Office of Special Education and Rehabilitation Services have noted the shortcomings of the categorical model of special education and the dangers of a fragmented service delivery system. Education policy makers are increasingly calling for a needs-based and supports-based system.



PATRICK SITS IN A CIRCLE ON THE FLOOR OF HIS PRESCHOOL CLASSROOM and offers two clues to help his classmates guess (per his teacher's instructions) about the object he has hidden behind him. "It's got glass pieces and piping," he accurately describes the hand-crafted bracelet he brought for show-and-tell. His parents and grandfather have come to school to help Patrick celebrate his birthday.

Patrick will be 5 years old in two days. He is excited to attend school, and he likes his teachers and friends there. He has friends from school with whom he plays at home. Patrick is a budding artist, and his work is appreciated at home and school. One of Patrick's large colorful paintings hangs in his family's living room. The extraordinary thing about Patrick's life is its ordinariness.

Despite the fact that he can occasionally express himself very clearly. Patrick has been diagnosed as having a communication disorder. But Patrick attends a public preschool classroom with non-disabled children — something his parents believe is very important for Patrick to learn to communicate. Patrick has normal intelligence and is like other children except for his communication problems. Still, his parents had some difficulty finding a program that matched Patrick's needs and their wish that he participate in typical school activities.

The communication specialist who evaluated Patrick at his neighborhood school believed that the school wasn't "equipped" to provide a young child like Patrick with the kind of intervention needed. The staff at the child care program Patrick attended also said they lacked the expertise to help. It took a while to figure out how to ensure that Patrick's eligibility for categorical services would enable him to obtain the assistance he needs to become a competent and confident communicator without taking him away from all the people and activities that Patrick loves and that give his life meaning. So now Patrick rides the bus to his inclusive public school program each morning, and from public school to his afternoon child care program each afternoon, while his parents work. Patrick's parents try to smooth transitions among home, public school, and community child care settings, and his teachers cooperate and support them in their efforts.

Even as they enjoy these ordinary pleasures, Patrick's parents worry about maintaining them. Next year Patrick will attend kindergarten, and his family has not yet received word whether Patrick will be welcome in his neighborhood school, or whether his eligibility for categorical services will mean a referral to a segregated special education classroom.



CATEGORICAL FUNDING. At the local school district level, administrators must be creative to support the costs of inclusive preschool services.

MONEY THAT SUPPORTS early childhood special education flows from federal, state, local, and private sources. State education administrators allocate federal and state funds, and at the school district level, officials blend these resource streams and secure local funds when needed to supplement them. Administrators must use funds creatively to address the complex and changing needs of children and families, while they accommodate intensive oversight of multiple programs.

- Special education is mandated by the federal government, funded through state governments, and implemented by local school districts.
- Publicly supported early childhood education programs are not available to all young children in the United States. Therefore, it is often necessary to combine programs to achieve inclusive environments.
- Some students with learning difficulties need individualized or more intense instruction. To find the resources, administrators turn to the reliable funding stream of special education.
- Categorical restrictions on programs and funding may force some early childhood programs to restrict special services to students with disabilities.

Although school districts enjoy some flexibility in their use of public resources for early childhood special education, federal law is precise and constant in the responsibilities for which it holds school districts accountable. Districts must evaluate every identified child to determine eligibility. They must provide appropriate services to children with disabilities. They must establish due process to ensure that families have appropriate access to services. And they must do so in the context of an increasingly diverse population of young children with multiple needs.





LOUISA IS A 3 YEAR-OLD AFRICAN AMERICAN GIRL WITH CHUBBY CHEEKS and a reputation for high energy and easy laughter. She is enrolled in a program at a large urban early childhood center. Louisa, in common with 500 other children attending her school, has a disability. She was born with a neurological disorder that affects her fine and gross motor, or physical, abilities.

Louisa's options for and access to learning opportunities could be severely narrowed by the complex administrative structure of her program. Seven major state or federal programs are housed at her school. But Lydia, the center's principal, has a breadth of vision that allows her to see through and beyond the practical and financial barriers separating the many categorical programs that she is solely responsible for directing.

One barrier that could hinder a unified program for children and families is access to funding. Lydia explains that she does not receive discretionary funds to support integration of various center activities. Realizing that this administrative barrier need not translate to a practical barrier, Lydia finds money from other sources "to make sure that everybody is on the same page."

Children with disabilities, like Louisa, receive invaluable opportunities to learn from their non-disabled peers in the context of group activities with a "buddy" classroom. Lydia tries to assure that all children and families have access to educational resources no matter what label or funding source supports their participation. She institutes several school-level initiatives, such as a center-wide resource room that provides materials and activities supporting school-wide learning themes. "We purchase materials out of our school-based management money and house them in the library so that Head Start or any other person in my building can check them out and use them on an ongoing basis, "Lydia explains.

These seemingly small efforts exemplify one lesson from successful programs that create inclusive educational opportunities for children. Bureaucratic rules and guidelines need not translate into barriers for children, families, and educators, provided that creative administrators have the initiative and flexibility to "orchestrate" programs so that — as Lydia explains — everyone can "play" together successfully.



CATEGORICAL THINKING. School districts can adhere to the "paper" requirements of programs without meeting the real needs of children and families.

EDUCATION POLICY MAKERS and program administrators strive for policies that focus on family and child development, rather than on the requirements of categorical programs. With this approach, the needs of each child are established through assessment, then addressed through selection of the most effective components of various programs for that child. But much of school financing, staffing, and administration center on programs, not individual children.

- When schools adhere strictly to discrete program requirements, they may administer a complex mix of services that "look good on paper" but do little for children.
- Such approaches violate the central premise of truly inclusive policies — to promote young children's membership and participation in their communities.
- State and federal special education policies use the individual education plan (IEP) to involve parents in planning for and securing appropriate services for their children. But decisions about placement and services are often managed at the administrative and school district level, without family involvement.
- Inclusion requires program managers and administrators to create and enforce accountability mechanisms based on individual student outcomes, not program requirements.

For many young children in special education, child-centered programs and family involvement are available before they reach 3 years of age, at which point they move from early intervention programs to school-based programs. The transition usually involves a shift in services from a family and health model to a community and school model, and families are not always prepared. Increasingly, state special education policies are acknowledging the shift in programs at age 3 and working to make the transition less disruptive.



MITH A DISABILITY. He has sandy blond hair, blue eyes, and rosy cheeks suggesting that he is well-fed and well-tended. He is tall for his age and appears older than his 5 years. But despite appearances, Daniel does have a disability. He has attention deficit hyperactivity disorder (ADHD), and the accompanying fluctuations in activity level, attentiveness, and heedfulness that accompany this neurological condition.

Although Daniel lives with his grandmother Barbara, he regularly visits his mother, who lives nearby, and his infant sister. When Daniel was born, his mother was 18 years old and single. She married a man after Daniel's birth, but the brief relationship ended after both parents were incarcerated for domestic violence. About this time, Barbara assumed

responsibility for Daniel's care.

Barbara's life is complicated, and so is Daniel's. He spends most days in educational placements that are separated by time, distance, and thinking.

Despite medication and Barbara's careful monitoring, Daniel has been expelled from six child care centers during his short life. The only people who accept Daniel and stick with him — beside his grandparents — are the Head Start teachers who are required to by law. The program serves as Daniel's special education placement and the official answer to his diagnosis. When the part-time Head Start program is not in session, Daniel attends a second child care program. This means that Daniel spends as many hours in a car or bus — traveling from home to Head Start to child care to home — as he spends in his special education setting.

Daniel's Head Start teachers are competent educators, and they like Daniel. They believe the responsibility for the "special" part of Daniel's education lies with an itinerant speech-language pathologist who visits the classroom once a week and shadows Daniel or removes him from the classroom to work on his goals. His Head Start teacher is unaware of the content of Daniel's IEP.

Daniel faces a dilemma; he must try to learn the important skills of communicating, establishing friendships, negotiating and solving problems with others. But his teachers separate him from his peers. Not surprisingly, Barbara says sadly that "Daniel has no friends."

Daniel's teacher says that "Daniel is not the worst child in the class." But nonetheless, she says she is worried that her class may become a "dumping ground" for children like Daniel.

On paper, Daniel spends his days in inclusive settings. In reality, he is isolated from peers and from meaningful interventions.



CULTURAL CONTEXT OF EDUCATION. Cultural issues, as much as disability, may affect which children are deemed eligible for special education.

A SUBSTANTIAL SHARE OF CHILDREN enrolled in early childhood special education programs are trying to surmount barriers to learning that are related as much to their life circumstances as to clearly identifiable physical or medical conditions — circumstances such as lack of English proficiency and the lingering effects of poverty, domestic violence, parental drug use, homelessness, and unemployment. In our increasingly diverse nation, as funding for basic public education has tightened over the past decade, school officials have had to address needs the best they can, often by reaching into special education budgets for the resources to assist children who have difficulty learning academics, social skills, and classroom routines.

- National data indicate that children with disabilities are disproportionately of minority status and likely to be growing up in low-income, single-parent families, with grandparents, or in foster care arrangements.
- The rapid rise in special education enrollment over the past decade suggests that it is being used as an all-purpose intervention for many children who have culturally rooted difficulties fitting into prescribed classroom curricula and settings.
- Over-identification of children as eligible for special education services is now a political issue, much as lack of such services was an issue that helped lead to passage of the federal Public Law 94-142 in 1975.

Children with disabilities are more likely than all children to be poor. Federal law addresses this problem by providing Title 1 and other programs to meet the special educational needs of low-income children. National data show that race and ethnicity are also strong drivers of special education placement. For example, African American children are more likely than White children, and Hispanic children less likely, to be enrolled in special education placement because of mild mental retardation or serious emotional disturbance.





${f M}$ a ny people think of language and ethnic background when they hear

THE WORD "CULTURE." But culture incorporates other kinds of behavior and demographic changes. All of these changes may influence the content of education and how services are delivered and used.

For example, Joanna and Robert have created a new family — one that came about because of environmental factors and the stresses of modern life — that is becoming more typical for children with disabilities. When Joanna and her husband, Robert, watched their teenage daughter prepare to venture into the world, they talked of retirement and travel. Then Joanna's daughter from her first marriage died, and Joanna and Robert inherited five young grandchildern.

Joanna's daughter had been drug addicted and had lived in a violent relationship. At the time of her child's death, Joanna and she were estranged. Joanna says she "did some soul searching" before bringing her grandchildren, who were relative strangers, into her home on what she thought would be an interim basis. "But ... now they are so bonded to us,... and we're so in love with them, we don't want them to go somewhere they might not get the same care." Joanna and Robert demonstrate a 24-hour-a-day commitment to their grandchildren, who early in their lives experienced parents who abused drugs and were chronically neglectful.

Two of the children, including 3 year-old Rachel, were diagnosed with fetal alcohol syndrome. Rachel also had been physically and sexually abused. Many of Rachel's problems, in common with those of a majority of young children served in special education settings, are invisible at first glance. She is a healthy child who charms her teachers and the high school students who help in her inclusive school program. But Rachel is often confused by verbal directions, is easily frustrated and angered, and doesn't play or make friends easily.

Rachel's school and community respond to these increasingly prevalent child and family circumstances with anger management classes and mental health counseling for school-age children, seminars to help families understand the dynamics of fetal alcohol syndrome and child maltreatment, early intervention in inclusive classrooms, and a willingness to work with families to solve problems.

Joanna believes strongly that "there is a way" of teaching children with Rachel's problems in school. "Whether or not the school system wants to adapt to them, that is what they are going to have to do, because there are going to be a whole bunch of them. When you see all the drugs and alcohol being used by young people, all the teenagers giving birth, all the children who are going to have problems and who don't have families Schools need to provide."



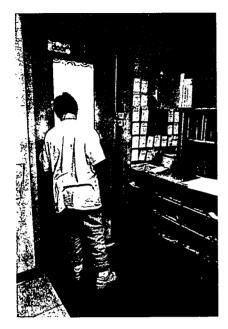
COMMUNITY CONTEXT OF EDUCATION.

School districts are run locally, and they reflect local values about special education.

LOCAL CONTROL OF EDUCATION POLICY is an established principle throughout the United States, particularly in more rural regions. Most school districts are run by locally elected boards of education and thus adhere to policies reflecting local political cultures. Each community views special education within its own concept of equal opportunity.

- The federal and state governments create most early childhood special education policies, but local school districts run programs. Increasingly, this dichotomy is a source of complaint from local school boards.
- Some school districts— such as those near tertiary medical centers for children — are responsive to the therapeutic needs of children with disabilities. In others, children with subtle developmental problems may not be seen as disabled.
- Some small to mid-sized school districts have been successful with inclusive classrooms because communication with teachers, families, and the community is direct and informal. School districts that encourage schools to experiment with multi-age groupings and alternative curricula, for example may also be more likely to embrace inclusive models. Many very small school districts have made inclusive classrooms work because it is their only option.

The current devolution of public policy-making authority and resources from the federal and state level to the local level enhances the role of communities in achieving inclusion in schools and other settings. Advocates for early childhood inclusion stress that it is an issue for communities as much as for public education systems. Successful inclusion requires collaboration and community membership to achieve safe and positive environments that are suitable not just for children with disabilities but for all children.



ALICE IS A LITTLE GIRL WITH SPEECH DELAYS
WHO RECEIVES SPECIAL EDUCATION SERVICES

in her inclusive early childhood class in a school district known for exemplary inclusive education. Alice's mother believes in inclusion of all children, not just those with disabilities.

When the district was reapportioned and Alice's school began to serve children who live in multifamily dwellings and who come from low income families, Alice's mother was not among those who removed their children and placed them in private schools.

Alice's mother describes her 5 year-old daughter as a "gap kid" whose problems are not severe but who "needs a little help." She says she favors mixed-age classrooms of children whose development and skills are at different levels, and she seeks inclusive class-

rooms for Alice. But she points out that "Alice could be in her [neighborhood] preschool in any event" because her developmental disability is so mild.

Alice's mother says she supports inclusion "across the board." But she adds that in some classrooms, the policy "takes time out from the teachers and the other things that are going on in the classroom." Some of the children, in her view, may not "fit."

At first glance, the children who don't fit in are not easy to find in this school, which has an exemplary reputation. The school's classrooms have dramatically high ceilings full of light and space. Children spill happily into the hallways with their cooperative projects, and they conduct thoughtful discussions about how people can solve conflicts in a peaceful manner.

But to find the children who don't fit in, one must walk no farther than to the end of the hall. There is no art work displayed on the walls here, no groups of children working. It is quiet and still. Here, hunched over a typewriter, is a boy with bushy red hair. His frame is too big for the desk and chair on which he is perched, and he looks uncomfortable as he stretches his long legs to one side to accommodate the lack of space. His fingertips touch the raised dots that represent letters and numbers in the Braille system.

Alice and the other young children from her inclusive child care program walk down the hall and descend the stairs to the gym. They are doing their best to keep their "lips zipped" as they have been instructed to do. The red-haired boy diligently types away. The preschool children pass quietly by.

The ethos of inclusion seems to translate differently in different locations and by different people.



PROFESSIONAL DEVELOPMENT AND PRACTICE. Inclusion requires teachers and staff to learn — and relearn — the basics of teaching young children with disabilities.

WHEN SPECIAL EDUCATION POLICIES CHANGE, administrators, teachers, and therapists are called upon to alter established methods of providing services. Inclusion inevitably alters the environment in which both regular and special education teachers work. To achieve successful change, teachers need special training and support. Efforts to assist change must be rooted in real-world circumstances and focused on the needs of children with disabilities, or they risk becoming sporadic, parochial, and disintegrated.

- With inclusion, special education teachers who are accustomed to working in a self-contained classroom often must learn new roles as itinerant teachers or team teachers.
- Special services for young children including Head Start and therapeutic child care — are often dispersed. This means that training in these areas is also dispersed, a situation that may discourage seamless and rational early childhood special education programs.
- Every state education department receives some federal funds to support personnel development, and most states use some of their own discretionary funds to train teachers. At the local level, school districts provide some form of continuing education for teachers.

Successful inclusion requires that educators and administrators from multiple disciplines receive coordinated training beginning in colleges and universities and continuing with professional development activities as they practice. Interdisciplinary training — drawing together regular education teachers, special education teachers, therapists, and social workers — can give professionals the information and support they need to accommodate a diverse group of students and to work in concert.



THE N ANYONE ASKS LORA ABOUT HER SON MARK'S DEVELOPMENTAL PROBLEMS,

she usually looks the person straight in the eye and asks, "Why don't you ask my son? He's right here." Mark's response is, "My body has earthquakes."

Mark is an attractive 4 year-old boy with long, blond hair pulled back into a braided ponytail. He wears a helmet for protection in case of a seizure. In his Head Start classroom, Mark has frequent tantrums and shows a lack of compliance with classroom routines. He speaks rarely, but on occasion surprises everyone by issuing full, clear sentences. Mark uses sign language about half the time and verbal language the other half. Lora says that "when he needs to tell me something important, and when he's really serious, he'll sign." Mark also has delayed fine motor skills, and he is unable to zip or button his clothes. Yet his

cognitive skills are two years advanced.

Mark and Lora have both learned that early childhood teachers are not necessarily prepared for inclusive programs. Lora removed Mark from a previous school program when she learned that Mark's teacher, after nine months with Mark in her classroom, did not know that Mark could talk. Lora reports that Mark was rarely involved in social activities in his previous classroom because his teachers "didn't know what to do with him and didn't want to upset him."

Recently in Mark's classroom, a boy took a truck Mark was playing with. Mark emphatically signed "stop" to the little boy. When the boy refused to return the truck, Mark resorted to wrestling with the boy. The teacher intervened, gave the truck back to Mark, removed the other boy, and seated him alone at a table. Lora would never tolerate that sort of behavior from Mark, whom she wants "to be treated the same as everyone else." Instead, a little boy was punished without understanding why, and without learning what Mark was trying to say. Mark's attempts to communicate were futile, and he missed an opportunity to learn the important art of negotiation. And the teacher remained lacking in competence.

When Lora is asked whether Mark has difficulty following directions, listening, and working in groups, Mark himself responds that he "doesn't really get that at school." Some things Mark would change about the program would be to have longer days and a summer program. Lora's ideal schedule would be a totally inclusive one, with therapy and behavior management available for all children in the classroom. Acknowledging that not all schools accept the responsibility to educate children like Mark, Lora says, "Well, they'd better become responsible because the world is inclusive."

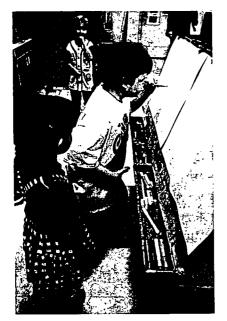




THE AUTONOMY EXPERIENCED by educators and administrators of early childhood special education programs is restricted by fear of litigation from families and advocacy groups. Legislation spells out the rights of students with disabilities and indicates the due process procedures available to families who believe their children are not receiving appropriate services. Truly inclusive programs for young children demand that teachers, school administrators, families, and advocates alike shift their focus from contracts, rights, and due process to collaboration and community-wide solutions.

- For some families and advocates, inclusive programs may appear to jeopardize hard-fought gains in rights and access to one-on-one education and therapy services for young children with disabilities.
- When educators and administrators cannot resolve disputes with families about inclusion or special education services, these disputes may escalate quickly into costly legal conflicts. Some educators use mediation to resolve issues with families.
- Teachers' unions often help shape special education policies at the classroom level. But providers of child care and early childhood teachers outside of public school settings are rarely union members, and they usually earn lower salaries than do public school teachers and the special educators who consult in their classrooms. Advocates are seeking a "worthy wage" for them.

The legal "standing" of inclusion — especially in early childhood programs — is unclear, and this makes for some confusion and concern among education policy makers and administrators. Inclusion is not explicitly mandated in federal special education law. Nor is there a standard definition used by all states for "least restrictive environment." But the principle of inclusion is implicit in the key piece of federal special education legislation, the 1990 Individuals with Disabilities Act (IDEA). And it has been affirmed in several court cases.



HER SON ADAM'S EARLY CHILDHOOD

CLASSROOM and anticipated a friendly chat with Dennis, the classroom assistant. But Dennis did not greet her with his usual banter. Instead, he wordlessly pointed to a sofa in the reading area of the classroom. On the sofa, Adam sat quietly and held an ice pack against his ear. Blood-spotted paper towels lay scattered on the carpet around his feet. Dennis simply whispered, "Matthew."

Kimberly scooped Adam and his belongings into her arms and marched into the center director's office, but she found it empty. She and her husband later requested a meeting with the center director and the classroom teachers.

This was not the first time Matthew had acted aggressively toward Adam, and they assumed it

wouldn't be the last. They had learned that Matthew had hurt other children in the class as well. They feared for their child's safety. They wanted Matthew removed from the classroom.

The situation could easily have led to contentious negotiations between parents and staff, and even to litigation. But the program's response reflected the way it has always honored the families it serves. The center operates long hours to accommodate working families. Each of its classrooms includes children with disabilities and the staff includes an adult with disabilities. A bulletin board highlights a different family of the center with stories and photographs. Hungry children may awaken from naps and groggily shuffle in their slippers to the kitchen for some fruit.

The program director arranged a meeting to include Adam's parents and his teachers. The substance of the meeting was not about Matthew, but about the Masons' concerns for Adam's safety. The school staff asked what they could do to help the Masons feel comfortable and confident. They assured the Masons that they would work with Matthew and his family to help the child learn to solve problems without violence. The message was clear: The behavior was not all right in their school, but the child was. The next day, Adam and Matthew played happily together.

In another preschool, parents organized to complain about a child with a disability who bites his classmates. After long and painful transactions between the school and families, the 4 year-old child with the disability was removed from his inclusive classroom in his neighborhood school. Many observers in inclusive classrooms have noted that conflicts between typically developing children are often accepted. But when a conflict arises between a child with disabilities and a typically developing child, it is considered aberrant.



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special education programs are exposed to several layers of federal and state regulation to ensure compliance with public policies and accountability for resources. When school districts do not adhere strictly to public mandates, they expose themselves to crippling fines and expensive changes in procedure. Regulation is a necessary burden that consumes staff time, generates paperwork, and requires strict adherence to mandated procedures and timeliness. But regulation that discourages creativity and flexibility in programs, and is unrelated to measures of program quality, serves as a barrier to preschool inclusion.

- Local school districts invest time and staff resources to establishing
 a "paper trail" for auditors, who inspect budgets and spending and
 check to see that special education assessments are timely.
 The paperwork demonstrates strict adherence to rules, not true
 accountability.
- Despite pressure to adhere to federal and state policies, early childhood special education assessment practices and classification often differ between states and even between districts.
- Regulations governing transportation and apportionment may entail trade-offs for families seeking inclusive programs. These trade-offs include long bus rides instead of neighborhood schools, and half-day instead of full-day enrollment.

By what measures can states and school districts determine if they have met both the legal guidelines and the spirit of inclusive special education policies? The benefits of inclusion are fundamentally difficult to measure. In addition to educational outcomes, they include social and behavioral skills, personal adjustment, independence, satisfaction, and community membership. These are complex outcomes to discuss with parents, local communities, and especially policy makers.



HARLIE IS THE GREGARIOUS, MIDDLE-AGED FATHER OF TINA, a typically developing teenager, and Sydney, a young child with Down syndrome. Over the past year, he has become increasingly frustrated with his children's schools.

Charlie has worked hard the past five years garnering educational and therapeutic support for Sydney. He describes his 5 year-old daughter as "real adaptable" and says she "seems to fit no matter where she is." Sydney is an animated child who usually makes friends wherever she goes.

When Charlie and his family moved recently from one large West Coast city to another, they began the process of finding a preschool that would match Sydney's special education needs. They were no longer novices at securing services, but moving to a new city when one has a child with disabilities can be

challenging no matter how experienced the family. Charlie describes the process of gathering support for Sydney in this way: "I was given a hundred different 'phone numbers, and no one could help me.... I was sent to so many places, and there was no central place" So Charlie learned that "you have to be your own advocate" in order for one's child to receive adequate services.

Charlie's search ended when he found a child care program to supplement Sydney's public school special education program. Sydney developed strong bonds with her teacher as well as with the other children in the program. Her parents recognized the quality care Sydney was receiving and were favorably impressed with services they believed were important to Sydney's development. One of the features they valued was the opportunity for Sydney to learn from typically developing children in a natural environment. This goal was stated by and strongly supported in Sydney's child care. Sydney and her child care program were a good match.

But because of the district's strict adherence to regulations, Sydney did not stay at the child care program that she and her parents liked so much. The public school that provided Sydney's transportation between school and child care informed Charlie that the child care was located outside its legal boundaries, and it would no longer transport Sydney. As a result, Charlie was forced to find another child care program located within the boundary of the public school transportation system. The only child care with space available served more than 40 children, and in Charlie's opinion, it didn't serve them well. "Sydney regressed drastically," Charlie reports. "It was a shock for us." Sydney has struggled in the program, despite her ability to fit in. Her adaptability — like a school system's — has limits.



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EBB AND FLOW OF PUBLIC DOLLARS. Local districts sometimes struggle to finance special education.

INCLUSION POLICIES require long-term funding commitments to work. Although "new" money for special education enjoyed widespread political support during the 1970s and '80s, policy makers in the '90s have been seeking ways to control spending. About 56% of special education "excess costs" — costs over and above regular education — are covered by state funds; this share varies greatly from state to state. Less than 8% of excess costs are covered by the federal government. When mandates remain in place without sufficient public resources to support them, district management may become idiosyncratic and reactive.

- In some districts, officials may configure inclusive classrooms to cut costs. In others, they may retain segregated programs to draw upon categorical program dollars. With either approach, long-term, preventive perspectives may be lost.
- Spending on preschool special education services varies across states, from less than \$700 a year per child, the amount allocated through federal Section 619 Preschool Grants, to more than \$6,000 per child.
- Faced with fiscal pressures, districts may become less aggressive in identifying children for preschool special education. Children with subtle problems may be served in other systems than special education, such as Head Start or child welfare. When pressures become particularly acute, they may not be identified or served at all.

Over the past decade, many states have pursued special education financing reform as they attempt to reconcile fiscal pressures with meeting the needs of students with disabilities. Although federal and most state laws define special education as an entitlement, several states have recently moved from a financing system based on the number of individuals who qualify for services to one based on a percentage of total school enrollment. For districts with high shares of special education students, this funding method may halt recent progress in identifying eligible young children for services.



PUZZLING CHILD to his teachers and to his parents. He has never received a clear diagnosis for his developmental problems, but at 4 years old, he cannot use language. The frustration he feels in making others understand him is apparent in his tears, his unintelligible protests, and his inability to enter social situations with other children. Christopher's mother believed at one time that he would "outgrow" his problems. But as time goes on, it becomes evident to her, and to Christopher's teachers, that his problems may not go away. Christopher will probably never be like most other children in his ability to talk, to play, and to learn.

Christopher's teacher, Karen, has stood by Christopher and his parents as she has with innumerable families during two decades of teaching. Karen

established one of the first inclusive early childhood programs in her state. She used volunteer labor and community donations of materials and equipment. Karen has held onto her clear philosophy that children with disabilities should be educated with typically developing children, and she has maintained a personal commitment to obtain the knowledge and skills she and her colleagues need to operate an inclusive preschool program.

Karen and her assistant teacher serve 16 children with disabilities during a five-hour session, four days a week. Their classroom is shared with two other early childhood educators and 16 more children who are typically developing. To assure the children get the individual attention they need, Karen has a small army of dedicated high school students working in the classroom. But those students need training, mentors, and support, so Karen's job is doubly hard, and she must answer to several different authorities.

Karen has been a creative, respected, and tenacious leader during administrative changes and building construction, according to her colleagues. But Karen believes that school funding reform in her state, which changed special education finance from a per-child allotment to a district block grant, has put program quality and availability at risk. "We are at maximum capacity," Karen says.

It is Karen and her colleagues in schools who must cope with the reality of the budget cuts and funding shifts demanded by policy makers and administrators. Karen worries that she will be forced to consider giving up the inclusive program in either the morning or afternoon. But though programs disappear, Christopher Matthews's developmental problems, and his need for education in the company of his peers, will not. Nor will his parents' need for information and support. Nor will Karen's desire to respond to those needs.

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cost of inclusion. Educating children with disabilities in typical settings undeniably affects special education costs, but no one knows how.

DO INCLUSIVE EARLY CHILDHOOD special education programs save or cost money? Academic research as yet offers no real answers. Administrators' perspectives vary according to experiences in their own programs. School district and state education agency data collection efforts lack the long-term, detailed tracking necessary to compare costs of inclusive programs with those generated by other approaches. The variability with which funds are allocated, administered, and spent across catagorical programs further complicates the picture. Advocates often refuse to discuss the cost issue, focusing instead on whether inclusion is the best policy to prepare all students for their place in a democratic society.

- Districts may embark on inclusive policies expecting to reduce the costs of operating parallel systems. But inclusive approaches may bring added costs in transportation and staff support.
- Additional costs of inclusion may occur in hiring more teachers, paying tuition of children with disabilities in private child care programs, providing continuing staff development opportunities, and in conducting more individual planning and problem solving.
- A precise calculation of the costs of inclusion would require documentation across budget categories and would include costs of transportation and training.

Federal and state agencies during the 1990s have learned to save costs by shifting clients, when possible, to other programs for which they may be eligible. It has recently become common practice, for example, for children with disabilities to be enrolled in federal disability programs to reduce fiscal pressures on states. Inclusion contradicts this trend by bringing individuals, programs, and budgets together, by emphasizing collaboration, and by blurring boundaries of agencies and jurisdictions. This is one reason why the costs of inclusion are so difficult to quantify.



EDDIE IS A 5 YEAR-OLD WITH A RADIANT SMILE AND FRIENDLY COUNTENANCE who attends an urban Head Start program. She qualifies because she comes from a low income family, but her teacher worries about her development as well.

Eddie is in some ways one of the more mature children in class, acting as helper with younger or disabled classmates. But on some days, she arrives at school too tired to participate, choosing to go silently to the library and suck her thumb. Some days, rather than helping other children board the bus, she will cry and cling to her teacher's hand until she is carried to the bus. Her teacher has taken the first steps to referring Eddie to special education.

The rise in use of early childhood special education services is due only in part to liberal eligibility criteria. Another significant driver is the type of

home environments children are experiencing today.

A school psychologist explains: "I think it's kind of a sign of the times. You know, we have more families with difficulties. And we've had an increasing number of children that have a history of drug exposure ... and that seems to have an impact on social and emotional development. Families are splitting up ... and there are social difficulties in families, difficulties with coping and parenting skills, so children are reported as having behavioral problems."

Many developmental disabilities, such as those that manifest as speech, language, or social skill differences, are subject to interpretation by individual families and professionals and are influenced by cultural standards and beliefs. Unlike academic skills, they are the most immune to change, even when children are enrolled in early child care and education programs. These types of disabilities have been referred to as "the new morbidity" because they are closely related to the social and economic changes in our nation that place children "at risk" for school failure and developmental problems. These are the types of disabilities that occur most frequently among children using special education services.

Children, families, and teachers all feel this bind. In the Spring, a rapidly growing suburban school district may open a temporary classroom to accommodate the children identified through "child find" developmental screening clinics. But a classroom that opens in mid-April may disappear less than two months later.

Some states are considering a "means test" for access to early child-hood special education programs. Many children currently receiving services may not meet more stringent income or developmental requirements. Instead, they will wait to fail in kindergarten or first grade before they are identified as needing services.



GLOSSARY

Advocacy organization: Advocates and advocacy organizations plead the cause of another, before lawmakers, courts, counselors and others.

Blended funding: The combining of federal, state, and local school district funds to finance complete at the classroom and school level.

district funds to finance services at the classroom and school level.

Chapter 1 program: Now officially "Title 1" of the federal Elementary and Secondary Education Act, Chapter 1 language refers to programs that improve opportunities for educationally deprived young children by helping them to succeed in school.

Discretionary funding: Public spending for which administrators exert some policy flexibility because its purpose is not strictly defined by federal or state statute.

Due process: A hearing for the resolution of conflicts regarding the educational identification, evaluation, or placement of a child.

Excess costs: The cost of educating special education students in excess of the funds provided for basic education.

Free appropriate public education (FAPE): A suitable education with emphasis on a student's special needs, provided at no cost to the parent or legal guardian.

Head Start: Federally mandated and financed preschool programs for low-income 3-5 year-olds. The federal law requires that 10% of Head Start enrollment be made available to children with disabilities.

Individuals with Disabilities Education Act (IDEA) Part B: The 1990 law, renaming and replacing the 1975 Education for All Handicapped Children Act, that is the primary legislation mandating special education for all eligible children.

Inclusion: A policy that all children with disabilities will be served in the school or child care of parents' choosing in settings with non-disabled peers.

Least restrictive environment (LRE): An education setting that is most like that in which children without disabilities are educated. In LRE,

children receive a full continuum of services that is individually

Means test: Criteria determining eligibility for publicly funded services.

Self-contained classroom: A classroom providing specialized training or instruction to pupils with disabling conditions. **Special education program eligibility:** To qualify for special education services, children must have a disability and also meet eligibility requirements as defined by state administrative codes.

Section 504 of the Rehabilitation Act: The section of the 1973 federal law that prohibits discrimination on the basis of physical or mental handicaps in federally assisted programs.

Section 619 of IDEA: The section of the federal special education law that provides incentives for states to ensure FAPE to children ages 3 to 5 with disabilities.



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AFTERWORD

MAKE A SINGLE POINT: that all special education policies for young children inevitably amount to a child, in a classroom, reconciling his or her disability with the same needs all children have to learn, to have friends, to feel loved and valued.

The stories of some of the children in these pages — those whose families, teachers, and communities work effectively together — show that, given hard work and commitment, inclusive programs can meet these goals.

But for other children we have come to know in our research, inclusive early childhood programs are barely meeting the letter — and not the spirit — of federal and state special education policies. For the same system that pledges services to children with disabilities can also withhold them. The special education system may deny

withhold them. The special eduneeded supports because of funding cutbacks. excesequately prepared perpolitical will to ensure ments address the needs able children.

unsuccessful outreach, sive regulation, inadsonnel, and the lack of that preschool environof even the most vulner-

The portraits also show that families of children in early childhood special education programs frequently accept compromises. To secure inclusive opportunities and needed services, many families relinquish the opportu-

opportunities and needed services, many families relinquish the opportunity to send their children to neighborhood schools (those who know they have this option). To place their children in inclusive settings for a few hours a day, families may endure complex schedules that keep children moving among a patchwork of services. And as many families attempt to access services that are guaranteed them under federal and state law, they experience frequent disappointment and lowered expectations.

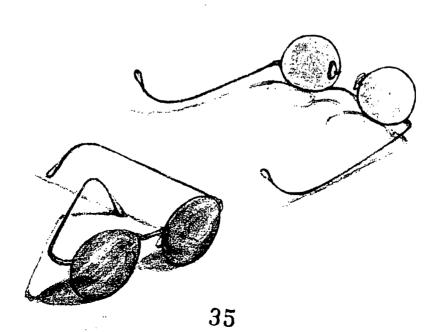
Undoubtedly, progress has occurred in achieving inclusive environments in early childhood education. Most advocates for inclusion would allow that it remains a great challenge, but they suggest that we "measure up" from the isolation and institutionalization that characterized programs for children with disabilities only a generation ago, rather than "measure down" from the ideal articulated in public policies.

The words of these policies are still stirring. A "free appropriate public education" in the "least restrictive setting" has been the promise of U.S. special education policy for more than two decades. For many children and families, that promise is beginning to be realized.





"Any public policy
essentially represents only a
wish — a goal that what the
law says will be met."









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